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ABSTRACT

This pamphlet answers questions parents often ask about employment and financial assistance opportunities for their children with disabilities who are exiting the school system. The questions are organized within the topics of transition planning, eligibility for financial aid, receiving benefits, impairment-related work expenses, living arrangements, wills and trusts, and other entitlement. A bibliography lists seven suggested readings, and a list of local, state, and national organizations is included. (JDD)

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LIFE AFTER SCHOOL FOR CHILDREN WITH DISABILITIES:

Answers to Questions Parents Ask About Employment and Financial Assistance

1997

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Foreword

Parents of children with disabilities are increasingly concerned about what happens when their children exit the school system, especially in terms of employment and financial assistance. The confusion surrounding these topics sparked our conviction that there is a need for clear information to answer parents' questions.

Although this publication cannot cover every situation, it does offer questions and answers parents may use as a guide to help them through some aspects of the transition process. The National Association of State Directors of Special Education (NASDSE) has developed this brochure under a grant from the National Institute on Disability and Rehabilitation Research of the Office of Special Education and Rehabilitative Services, (OSERS), U.S. Department of Education. Copies will be distributed nationwide through the schools and by interested organizations.

NASDSE appreciates and acknowledges contributions of parents who suggested questions through the National Parent Chain or who talked with our interviewers, and of our reviewers for their ideas and suggestions. The reviewers included Carolyn Beckett, Margaret Burley, Delores John, Anne Lawyer, Cory Moore, Carol Rewers, Suzanne Ripley, and Cathy Wetherby, as well as the Social Security Administration. Special thanks are expressed to Madeleine Will, Former Assistant Secretary, OSERS; Patty Smith, former Deputy Assistant Secretary, OSERS; and Carol Inman, former Deputy Assistant Secretary, OSERS, for their encouragement and support for this project.

We also express appreciation to Eileen M. Lavine and Joan Z. Romeo of Information Services, Inc., Bethesda, MD, who researched, wrote, and produced this publication.

William V. Schipper
Executive Director
NASDSE, Inc.

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Preface

What will happen when your child finishes high school? Parents who have children with disabilities naturally want their children to have every opportunity for achieving their fullest potential - but they are often bewildered about the next steps.

This pamphlet is intended as an overview to help you work your way through the maze of questions that arise as you and your child plan for the future.

Your local school system is most likely taking major responsibility for planning during your child's school years. But as you look to the future, you may not feel adequately prepared to plan for the post-school years.

Will your sons and daughters be able to get jobs? Where will they live, whom will they live with, and what kind of economic support, if any, can they count on?

The information in the following pages was developed from actual parents' questions. Some of them have been suggested by parents who have already been through the experience. The questions and answers focus primarily on work incentives and financial assistance for young people with disabilities.

The answers will help families see that, in most cases, the benefits of employment can far outweigh concerns about financial aid. Work incentives help young adults develop self-confidence and can support them on their way to financial independence. Also, rules and regulations change frequently, so please be sure to check with the appropriate local and state agencies to verify information you read.

Our answers are not the final word, because there are so many variables among individuals, between states and local areas. However, these guidelines show a continuing process that will assist in setting targets for you and your child. Be persistent and learn to get your own answers, using the "Resources Section" of this booklet as a starting point.

The transition from school to community living is complex for everyone. For the young adult with a disability and his family, this change brings many questions. We hope this booklet will act as a guide to asking those first questions and identifying state and local resources.

Transition Planning

1. How can I make the transition from school to the real world easier for my child who has a disability?

Starting early to plan the transition is essential - even elementary school is not too soon. It is important to think about the skills your child will need to develop - personal, social, and vocational - to prepare him for a meaningful and purposeful life. An Individualized Education Program (IEP) that includes functional and practical skills and that is developed early in the school years will smooth the way and help the adult service system to plan and provide support services. REMINDER: States designate cutoff points at which children are no longer eligible for public school services. Check with your state or local education agency to find out the cutoff age.

2. Who may help in the development of an IEP that will prepare my child for work?

In addition to contacting his special education teacher, resource person, or program coordinator, you may also want to contact a local vocational rehabilitation counselor and/or vocational education special needs' adviser for information about courses that will have practical value. The state office of Vocational Rehabilitation can tell you where the local rehabilitation counselor can be found, or you can contact a city or county social services' office. Some local education agencies have a Special Needs Coordinator for Vocational Education.

3. What can I do now for my junior high school daughter to help her to work and live more independently when she completes school?

Take a close look at vocational programs to see what training is available. The Carl D. Perkins Act mandates vocational/transition planning in public schools for children with disabilities. Now is the time to ask the school about vocational assessment of skill areas such as work readiness, interests, social adjustments, aptitudes. These will provide the basis for determining vocational or employment strengths and needs. Introducing work skills now will help your child in the years ahead. Be sure the IEP includes necessary training in these areas. You can help your child develop independent behaviors at home - shopping, cooking, laundry, clothes selection. If you feel that you need help, remember that many states have parent training and information groups that offer guidance and information and conduct workshops and seminars. Perhaps a transition planning team made up of

parents and representatives from school, vocational rehabilitation, and the business community may be arranged

4. Are there internships available so that my son can have some supervised work experience before he finishes school?

Many schools now offer part-time internships for students with disabilities to acquaint them with work situations. This should begin several years before he finishes school. Opportunities and eligibility requirements vary from state to state, and sometimes from county to county, so check with your local education agency.

5. What types of work settings will be available for my daughter when she finishes school?

A variety of employment programs are offered in many states. Talk to your school transition team about identifying these programs in your area. These usually include a number of options:

a) competitive employment - a regular job in an actual work setting working with non-disabled people.

b) supported work model - job placement and on-the-job training with a "job coach" and follow-up services within an integrated, competitive setting.

c) enclave - a variation of (b) with jobs within a business or an industry for a group of individuals with disabilities, where a staff person provides full-time supervision.

Although states also fund segregated work and vocational skill development programs (such as sheltered workshops and work activity centers), many states are de-emphasizing these programs.

Eligibility for Financial Aid

6. On what basis would my child be declared eligible for financial aid?

To determine if a person is eligible to receive Supplemental Security Income (SSI), the Social Security Administration (SSA) - which administers SSI -evaluates whether the person is unable "to do any substantial gainful activity by reason of any medically determinable physical or mental impairment

which . . . has lasted or can be expected to last for a continuous period of not less than 12 months."

7. What is "substantial gainful activity?"

The Social Security Administration defines "substantial gainful activity" or SGA as "the performance of significant duties over a reasonable period of time in work for remuneration or profit or in work of a type generally performed for remuneration or profit." A person earning more than $300 a month is generally considered to be doing substantial gainful activity (for statutorily blind, contact your local social security administration office). This is the 1988 level and may change from year to year. Special SSI payments - referred to as 1619(a) and (b) - enable permanently disabled SSI recipients with low to moderate earnings to receive reduced payments indefinitely, even if they earn more than the current SGA amount. The amount of income determines their eligibility. (See #16-18 of this publication for more details on this important work incentive made permanent by 1986 legislation).

8. My son has just turned 18. I have been told that he is eligible for financial aid although an earlier request was denied because our income was too high.

When your child reaches 18, your income and resources are no longer considered in determining whether he is eligible for aid. Now he may be entitled to Supplemental Security Income (SSI), administered through the Social Security Administration, if he (a) has little or no income or resources (parents' income is not counted); (b) is medically disabled or blind; and (c) does not work or works but earns less than the substantial gainful activity level (except as noted under #15).

9. When and where should my son apply for SSI?

It is wise to apply several months before his 18th birthday. Payments will not start until he is actually 18, but the application processing procedure takes from 2-4 months. You can apply at any Social Security office. Check your local telephone book under Social Security Administration for number of area offices; the number is frequently busy, so keep trying. Take your son with you and be sure to bring along the following:

- Birth certificate and Social Security number or card;
- Medical records about disability;
- Doctors' names and addresses;

- Information about savings accounts, trust funds, insurance policies, property, etc. (Remember that if these resources are over the limit, he may be ineligible.)

You may want to call your Social Security office beforehand to establish contact with an agency represensentative who is knowledgeable about SSI. Arrange an appointment in advance and see if any additional records are needed.

REMINDER: In your discussions with SSA, it's always a good idea to keep a record of (a) whom you spoke to and the date; (b) the information provided, etc. This gives you a good reference base if questions arise in the future.

Receiving Benefits

10. When my son's application is approved, how much can he expect to receive monthly?

The maximum Federal benefit rate for 1988 is $354 a month. Many states supplement the Federal benefit rate. The people in the Social Security office can tell you whether the state where you live pays a supplement.

11. Will my son's savings affect his benefits?

He will not receive SSI benefits if he has countable assets (stocks, real estate, savings, etc.) exceeding $1,900 in value. Non-cash assets such as a car* and the house in which he lives are not considered here, nor is money in a trust (See #27).

12. My daughter, age 19, is unemployed. She has no outside income and I provide her room and board. Can she receive full SSI benefits?

SSI benefits are for food, shelter and clothing. Gifts of these items (including rent, mortgage payment, taxes, and utilities), and gifts of money are counted as income, with a recipient's SSI benefits decreased as a result. Since you provide your daughter with room and board, her SSI benefits will be reduced by one-third; based on the $354 maximum, she would receive about $236 a month. Check with your local social security office for clarification before making gifts, purchases or payments.

* Car must be used for essential transportation, i.e., medical, employment, or be valued at $4,500 or less in order not to count.

13. What happens if my daughter finds work in a sheltered workshop or work activity center? Will her earnings be considered toward SSI payments?

Up to $85 a month of this "earned" income will be disregarded in calculating SSI benefits.

14. My daughter has obtained a part-time job, earning approximately $75 a month. She is currently receiving SSI checks. Will her SSI payment be reduced now that she is working?

If SSI was your daughter's only income before she started her job, she can earn up to $85 a month (gross pay) with no reduction in SSI checks. At $75, her SSI payments will stay the same. If her wages rise above $85 a month, her SSI check will be reduced by $1 for every $2 that she earns above $85. For example, if she earns $105 a month, or $20 more than the $85 limit, she will receive $10 less from her SSI check.

15. What happens to my son's SSI benefits if he finds a job and earns $200 to $250 a month?

First, be sure your son's job and salary is reported to your Social Security Administration office. Any special circumstances, such as work expenses related to his disability (special equipment, for example), if he is getting special help at work, transportation, etc should be cited. The new job may mean a reduction in SSI benefits, but these will probably be offset by what he earns. It is important that his salary be reported so that he will not be charged with overpayment of benefits. Social Security would require him to pay back any benefits that were overpaid.

16. My daughter has done well in her job and now earns $325 a month. Will her SSI benefits stop?

Probably not. She may be eligible for special SSI payments (explained under #7), reduced in proportion to her actual earnings. Even if she were to earn too much income to receive SSI cash benefits, she would still be eligible for Medicaid coverage.

Social Security offices across the country have designated work incentive specialists to help explain the new rules under 1619(a) and 1619(b).

17. How would this affect her specifically?

Her SSI checks would be reduced in proportion to her actual income increases. If her salary continues to rise, there is a break-even point, (currently $793 maximum), at which her earnings would cancel out SSI. For example, a person whose monthly SSI payment is $354 can earn up to $793 (gross pay). A person who receives less than $354 a month will have a lower break-even point. SSI recipients should know their break-even point - that is, how much they can earn without losing all SSI benefits.

To determine a break-even point, use this formula:

a)	Multiply SSI monthly amount ($236) by 2	$472
b)	Add	$ 85
c)	Break-evenpoint	$557

18. What would happen if she lost her job?

Your daughter can go back to receiving regular SSI benefits. She must report the loss of her job to SSA immediately so that SSI benefits will be increased or reinstated.

19. My son's SSI benefits stopped because his earnings were too high. Now he has lost his job. Does he have to apply all over again to get SSI benefits?

Your SSA office should be notified about the change in your son's work status; also, check to see if he still meets the eligibility requirements for SSI. If he does and his earnings have ceased, he is once again eligible for regular SSI benefits. No new application is necessary. Only individuals who have been ineligible for any SSI benefit for 12 consecutive months need to reapply.

20. How can my daughter save money for more vocational training without losing her SSI benefits?

Your daughter, with the help of her employer, vocational counselor, or advisor, can develop a Plan for Achieving Self-Support (PASS). This will enable her to set aside income and/or resources over a certain period of time for a specific work goal. The special income and resources set aside are not counted as income or resources for SSI purposes. (The Social Security Ad-

ministration provides a form, "Checklist for Plans for Achieving Self-Support," that outlines the format and information necessary in a PASS.) The SSA will evaluate the plan to see if it meets all criteria for approval.

21. We are moving from a large city to a small rural town in another state. Will my son still be able to receive SSI benefits?

As long as your son has a disabling condition he is entitled to receive payments. Contact the SSA to find out how to make the transition without losing benefits during the move and to determine if the state to which you are moving offers supplements to SSI. (See question #10.)

22. My son is interested in working. However, he has many medical problems, and I am afraid that if he goes to work, he will lose his Medicaid benefits. Is he protected in any way?

Yes, he may still qualify for Medicaid coverage, even if he earns too much to receive SSI cash benefits. The requirements are that: (a) he still has a disabling condition; (b) he needs Medicaid in order to continue to work; and (c) he cannot afford other health insurance. To qualify for (b), he must use Medicaid benefits at least once during the 12 months after he starts working.

SSA uses a special formula to determine whether an individual's earnings are sufficient to replace the SSI and Medicaid benefits no longer paid because of employment. This "threshold concept" varies from state to state; check with your local SSA advisor.

23. If my daughter goes to work, will she be eligible for health insurance if she does not get Medicaid?

She may be eligible. If she is not covered by her employer for pre-existing conditions, she may be able to buy into a risk pool for uninsurable people; about 15 states have risk pool insurance at present. If you have questions and want information on other private insurance options, check with your State Insurance Commissioner. Information about how to contact that office is available from the National Association of Insurance Commissioners, 1125 Grand Ave., Kansas City, MO 64106, telephone: 816-842-3600.

Impairment-Related Work Expenses

24. My husband and I both work. Our son uses a wheelchair, and he just got a job. He will need assistance in getting

ready to go to work and getting there and back home again. Who pays for the added expense of this assistance?

First, determine with SSA whether your son is eligible for SSI. Once eligibility is established, he may then consider deductions for impairment-related work expenses. This means that his costs, paid by your son, can be excluded from his earned income in determining his SSI monthly payment, which, in turn, should yield a higher payment. A list of deductible and non-deductible impairment-related work expenses is available from your SSA advisor with whom you should review these items.

Living Arrangements

25. Now that my son is 22 and working, we would like to see him live more independently. What types of facilities are there and how much will these cost?

Living arrangements will vary from community to community. The type of setting you are looking for will also depend on your son's level of independence and how much assistance he requires. Independent living complexes, group homes, or staffed apartments may be available, and he may be eligible for rental assistance under a program of the U.S. Department of Housing and Urban Development (HUD). If the state provides housing of this kind, residents with personal income, such as SSI, may have to pay a certain amount - but will be allowed to keep a portion for personal needs.

Be prepared to make application early for such housing to the appropriate agency in your state. (Check the Department of Health and Mental Hygiene.) Many state-run facilities have long waiting lists. Apply to your local Public Housing Agency or HUD office for information on rental assistance programs.

Wills and Trusts

26. What happens after we die? What needs to be done to take care of our child's future?

Careful estate planning is essential. You will need to determine whether it will be necessary to appoint a guardian for your child and/or for the estate. Find a competent attorney experienced in this field to help you draw up your will and talk to an insurance consultant about adequate coverage. Many dis-

ability associations such as the Association for Retarded Citizens may be able to make referrals. (See "Resources" at end of this publication.) Remember to review your will periodically - at least every five years - to see if any changes need to be made.

27. How can we structure our will so that an inheritance would not affect the SSI payment our child receives? What about money left by grandparents? Does this cancel SSI or other benefits?

You can set up a trust for your child with disabilities with a trustee to administer it. An attorney knowledgeable in these special cases can prepare your will so that SSI, Medicaid, and other benefits will stay intact. Grandparents and other relatives should be cautioned about leaving assets directly to person with disabilities. A useful booklet to consult is: "How to Provide for Their Future," Association for Retarded Citizens of the U.S., P.O. Box 6109, Arlington, TX 76011. (See "Bibliography" section for books on this subject and call the local ARC for names of attorneys experienced in handling estate matters for persons with disabilities.)

Other Entitlement

28. My husband worked and paid into Social Security before he died last year. My daughter, who has had a disability since birth, has been receiving Social Security Disability Insurance (SSDI) benefits since he died. Will she keep getting these benefits if she starts working after she leaves school?

SSDI benefits are paid to persons who became disabled before age 22 if at least one of their parents had worked a certain amount of time under Social Security but is now disabled, retired, and/or deceased. Your daughter's benefits will continue after she reaches age 18 if she can show that she became severely disabled before age 22, that immediate recovery is unlikely, and that she cannot perform substantial gainful activity. There are several rules designed to help her by continuing benefits while she tests her ability to work on a regular basis. They include a trial work period and an extended period of eligibility. [Note that she may be eligible for Medicaid after two years of receiving Social Security disability benefits.] If her Social Security benefits are low and she has little other income and resources, she may be eligible for SSI (Supplemental Security Income) disability benefits, too. Check with your Social Security office for details.

Bibliography

Alternatives, A Family Guide to Legal and Financial Planning for the Disabled. Mark L. Russell. First Publications, Inc., Box 5072 Evanston, IL 60204. ($18.95, including postage and handling)

Competitive Employment :Issues and Strategies. F. R. Rusch (Ed.). Paul H. Brookes Publishing Co., P.O. Box 10624. Baltimore, MD 21285. ($36.00 no postage and handling fee if ordered via Visa/Mastercard)

Employers and Parents Taking Action: Transitional Work Opportunities for Disabled Youth. Project Coordinator, Regional Information Exchange, Human Interaction Research Institute, 1845 Sawtelle Blvd., Los Angeles, CA 90025. $1.00

Financial Planning for the Handicapped. Don P. Holden and Charles Thomas. 2600 South First St., Springfield IL 62717. $35.75 + postage and handling

Getting Employed, Staying Employed: Job Development and Training for Persons with Severe Handicaps. Caven S. McLoughlin, J. Bradley Garner and Michael Callahan. Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285. $22.95 (no postange/handling fee if ordered via Visa/Mastercard)

Pathways to Employment for Developmentally Disabled Adults. W. Keirnam and J. Stark, (Eds.). Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285. $36.95 (no postage/handling fee if ordered via Visa/Mastercard)

Toward Independence - An Assessment of Federal Laws and Programs Affecting Persons with Disabilities - with Legislative Recommendations. National Council on the Handicapped, from Superintendent of Documents, Washington DC 20402 #052-03-01022-4.

Resources

Following is a partial list of local, state, and national organizations to contact for additional information and help.

Local Agencies

- Social Security Administration (listed in your phone book under U.S. Government, Department of Health and Human Services)
- Special Education Director of your school or local school district
- Vocational Rehabilitation Office
- Vocational Education Office for children with special needs
- Legal Aid Bureau (if you need inexpensive legal assistance)
- United Way (listed in your phone book; they maintain a listing of associated services)

State Agencies

You may request a copy of your State Resource Sheet which lists names, addresses and telephone numbers of state agencies and disability associations from NICHCY (listed under NATIONAL resources). You can also locate many of these resources in your phone book or by calling the special education director in your local school district.

Disability associations in your state which are concerned with issues similar to yours. (These may be listed with the local special education office or on the NICHCY State Resource Sheet).

- State Department of Education, Division of Special Education
- State Vocational Rehabilitation Agency
- Division of Vocational Education, Office for Special Needs Students
- State Mental Health Agency
- State Mental Retardation Program
- State Developmental Disabilities Program or Agency
- State Protection and Advocacy Agencies (there are two, one for clients with developmental disabilities and the other for clients with mental illness)

National

Administration on Developmental Disabilities, 200 Independence Avenue, S.W., Washington, D.C. 20201 (202) 245-2588

Council of State Administrators of Vocational Rehabilitation, P.O. Box 3776, Washington, D.C. 20007 (202) 638-4634

National Association of Developmental Disabilities Councils, 1234 Massachusetts Ave. N.W., Suite 103, Washington, D.C. 20005 (202) 347-1234

National Association of Rehabilitation Facilities, P.O. Box 17675, Washington, D.C. 20041 (703) 648-9300

National Association of Insurance Commissioners, 120 W. 12th Street, Suite 1100, Kansas City, MO 64105 (816) 842-3600

National Information Center for Children and Youth with Handicaps (NICHCY), 7926 Jones Branch Drive, Suite 1100, McLean, VA 22102 (703) 893-6061 or 1-800-999-5599 (to leave a recorded message). NICHCY will provide the State Resource Sheet at no charge.

National Organizations on Disability, 910 16th Street, N.W., Suite 600, Washington, D.C. 1-800-248-2253

National Rehabilitation Information Center (NARIC), 8455 Colesville Road, Suite 935, Silver Spring, MD 20910 301-588-9284 or 1-800-346-2742

Office of Special Education and Rehabilitative Services (OSERS), Office of the Assistant Secretary, U.S. Department of Education, Switzer Building, Room 4620, 400 Maryland Ave. S.W., Washington, D.C. 20202 (202) 732-1265

President's Committee on Employment of People with Disabilities, 1111 20th St. N.W., Room 636, Washington, D.C. 20036 (202) 653-5044

Special Advisor for Disability Issues, U.S. Department of Housing and Urban Development, 451 7th St. S.W., Washington, D.C. 20410, (202) 426-6030

State Medicaid Directors Association, 810 First Street N.E., Suite 500, Washington, D.C. 20002 (202) 682-0100